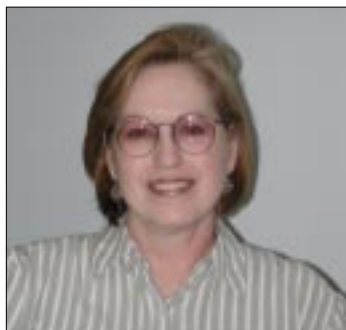


ASCC Welcomes Susan Hancock

Susan Hancock joined the Arkansas Spinal Cord Commission (ASCC) staff in April and has assumed the responsibilities of Batesville Case Manager. She is a graduate of the University of California with a degree in Sociology.

Susan has thirteen years of case management experience and brings a wealth of knowledge to the position. Having previously worked with individuals with many different disabilities, she is very adept at accessing information and locating resources.



Susan Hancock is the new Case Manager in ASCC's Batesville office.

Susan and her husband Elliott have lived in Mountain View for the past twenty years. She has one daughter, Willow, and one son, Ben. Her familiarity with the counties she will be serving is a definite asset.

Over the past few months changes have been occurring in several ASCC Case Management offices. Rose Trosper has transferred from the Jonesboro Office to the

Little Rock Case Management Office. She is replacing Dan Stell, who retired in February, and covers Faulkner and North Pulaski counties. Russell Henry has transferred from the Batesville office to the Jonesboro Case Management Office to replace Rose.

The result of these changes was the need for a new Case Manager in the Batesville office. ASCC is very fortunate to have found Susan with her excellent background.

The Commission members and staff of ASCC are excited to have such a qualified individual joining our agency. Please join us in welcoming Susan!

2001 Miniconferences Coming Up!

We know that not everyone can travel to Little Rock to participate in ASCC's *Living with Spinal Cord Injury* conferences. That's why since 1997 we have alternated the Little Rock conference every other year with regional miniconferences in local communities.

This year our first regional miniconference will be at the University of Arkansas Community College at **Hope** on Friday, **July 27**. The second regional miniconference will be conducted in collaboration with the North Arkansas Partnership for Health Education at the North Arkansas Community College in **Harrison** on Friday, **October 12**.

Each of the miniconferences will feature educational sessions on

topics including medical issues, community resources, health and wellness and new technology related to spinal cord disability. The target audience for the sessions will be people living with spinal cord disabilities, their families and care givers, and health care professionals such as case managers, nurses, therapists and other interested individuals. The miniconferences will also feature an opportunity to see the newest durable medical equipment and medical supplies. Lunch will be provided.

Mark your calendar now to attend one of the miniconferences! You will be receiving program and registration information in the mail as the dates come closer.

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SPINAL COURIER

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ASCC accepts tax deductible donations. The generosity of the many individuals and families, who over the years have made memorial donations, is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at **501-296-1788 / 800-459-1517** (voice), **501-296-1794** (TDD), or send your donation to:

AR Spinal Cord Commission
1501 N. University, Suite 470
Little Rock, AR 72207

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Do You Have More Than One Wheelchair?

Dear Editor:

One of my clients recently learned the hard way that Medicare will only reimburse for repairs on one wheelchair. This person has a manual and an electric wheelchair. He got reimbursed a small amount for replacement of a wheelbearing on the manual chair but soon needed to replace the batteries on the electric. When he submitted the much larger bill for the batteries, Medicare rejected it stating they

were already maintaining the manual chair.

So, if you have more than one chair you will probably be better off having Medicare repair the electric or more expensive chair and you pay for repairs on the manual or less expensive one.

Robert Griffin
ASCC Case Manager
Russellville, AR

From the Director

It happened again, and I'm back on my soapbox.

It was Memorial Day and a lovely young teenager, spokesperson for Mothers Against Drunk Driving (MADD), was in a motor vehicle crash on a Little Rock freeway. Ejected from her car, she died at the scene—17 years old! Would a seat belt have saved her life? Can't say for sure, but the friend riding with her, **who was buckled up, sustained only minor injuries**, though the car rolled several times. Such a waste of a young life! And so ironic, as it happened during *National Buckle Up Week*, when Arkansas police were out on extra duty, as part of a national safety campaign promoting the buckle up message!

There is no question in my mind that **seat belts save lives and prevent injuries**. I consider it just another little insurance policy every time I buckle up. Maybe Representative Jake Files of Fort Smith feels the same way. He sponsored a bill during the legislative session that requires children up to 60 pounds or 6 years old to be secured in child safety seats and children from ages 6 to 15 to be buckled up in seat belts. Or, maybe Mr. Files knows another young woman who was in a motor vehicle crash when she was 17—she lives in his area, and lives with a spinal cord injury and on a ventilator.

It's not worth taking the chance. Take a second and **buckle up!**

Cheryl Vines

Hendren Overhauls Disabled Parking Laws

Representative Kim Hendren came to the 2001 legislative session with a mission, to assure that people with disabilities are the only ones who use disabled parking spaces. Working with Governor's Commission on People with Disabilities Executive Director Barry Vuletich, he sponsored House Bill 1196, now Act 609 of 2001—an Act to enhance the penalty for parking in a disabled parking space and reduce the time period for issuance of disabled parking certificates. This is yet another step to strengthen the Arkansas disabled parking laws.

Act 609, which will go into effect on August 17, 2001, increases the penalty for parking in a disabled space. In addition to the present fines of \$100 to \$500 for a first offense and \$250 to \$1,000 for a second or subsequent offense, Hendren's legislation adds that upon the second or subsequent offense, the court shall suspend the driver's license for up to six months. That should get parking abusers' attention!

The Act also requires the Department of Finance and Administra-

tion to include a notice with all applications for special license plates or placards informing the applicant and anyone driving for the applicant of the fines.

The notice specifically informs them that the privilege to park in spaces reserved for people with disabilities shall be available **only** when the person for whom the plate or placard was issued or a person with a physical disability **is in the car**.

Finally, the Act makes two other administrative changes. It requires that special license plates or placards be returned to the State Department of Finance and Administration when a person moves from the state, or within 30 days of the death of the person to whom it was issued. This should prevent placards from being handed down like family heirlooms or sold at garage sales

(don't laugh—it has happened). It also decreases the period the placard is issued for from five to two years, but will not require additional medical certification to renew.

Thanks to the work of Representative Hendren of Gravette and Barry Vuletich, the bill sailed through the House and Senate and was signed into law by Governor Huckabee on March 7, 2001. The Arkansas Spinal Cord Commission extends our appreciation to Representative Hendren and Barry Vuletich for their work on behalf of folks with disabilities.

Now, parking abusers beware! You are warned in advance: illegal parking in spaces reserved for people with disabilities, even in a vehicle with a placard or special plate, could cost you a lot of money or your driver's license! It's not worth it—if you can walk the few extra feet, do it!

Illegal parking in spaces reserved for people with disabilities, even in a vehicle with a placard or special plate, could cost you a lot of money or your driver's license!

What You Should Know About CAPPS, Part I

Consumer Action to Prevent Pressure Sores (CAPPS) was a research project conducted by the Arkansas Spinal Cord Commission and funded by the Centers for Disease Control and Prevention. The purpose of the project was to determine if an in-home education program could be effective in preventing pressure sores in persons with spinal cord injury (SCI). Although this study involved only persons with SCI, the results can be applied to all persons with a spinal cord disability.

This article briefly summarizes the main points and some findings of the study.

Sixty-six Arkansans with SCI, aged 18 to 64, were recruited to participate. These individuals were randomly assigned to an intervention group or to a control group. The 33 persons in the intervention group participated weekly in in-home, pressure sore prevention education sessions conducted by a home health nurse. The control group received no education sessions. The prevention education material focused on four areas: skin maintenance, nutrition, equipment utilization and maintenance, and healthy living.

To measure the effect of the prevention education on the number

and severity of pressure sores, all participants attended three clinics. The presence and severity of sores were determined by a physician at the clinics during a medical examination. The first clinic was conducted before the intervention began. The second clinic was held six months later at the end of the intervention and before the monitoring period. The third clinic was conducted at the end of the monitoring period (12 months after clinic one). In the monitoring period, the intervention group was instructed to continue on their own with their pressure sore prevention

Continued on page 5 - See CAPPS Project

Vocare Bladder System

By Tom Kiser, M.D., ASCC Medical Director

After a spinal cord injury a lot of your body systems are affected. The ability to empty your bladder is one of those systems, and often individuals have to empty their bladder with a catheter, or for males, use their bladder spasms to empty the bladder and a condom catheter to catch their urine. Others go on to have surgery to help with bladder emptying and collection. An electrical stimulation system, which has been successfully used in Europe for approximately ten years, has recently been introduced to the United States. It is called the Vocare Bladder system, and was known as the Brindley device in Europe (named after its developer, Brindley).

The Vocare Bladder system is an implantable electromagnet receiver, which is usually placed on the abdomen under the skin. Wires from the receiver are then tunneled under the skin, and around to the sacrum where the bone on the top of the sacrum is unroofed to expose the sacral nerves. The wires end in a silicon-coated cuff, which are placed around the anterior sacral nerve roots at the S2-4 level. The sacral nerves are then stimulated to cause the bladder to contract and empty. They also can stimulate the lower bowel to empty and help with your bowel program. To allow the bladder to expand well and not spasm, the sensory nerve roots from the bladder are cut at a second surgical site higher up on your back after unroofing the bone over the spinal cord. The surgery takes about six to eight hours to perform, and you are usually in the hospital for approximately five days.

The advantage of the system is that it can be used to stimulate your bladder to empty without using a catheter, so the risk of bladder infections are greatly reduced. Usually the system can almost

entirely empty the bladder with less than 50 cc. left in the bladder. With a different stimulation frequency and duration, the bowels will also contract and the system can be used to help empty your bowels. For males, erections may be lost when the sacral sensory nerves are cut, however, at the time of surgery the surgeon can determine which sacral nerve roots cause erections and the system can be programmed to provide erections. Nonetheless, to achieve an erection the transmitter must be placed and held over the receiver the entire time. The use of Viagra and the Vocare Bladder system is being investigated to see how they work together.

The Vocare Bladder system is not for everyone. An individual with an incomplete SCI will lose sacral sensation and, therefore, is not a candidate. You need to have reflex bladder contractions, which can generate adequate bladder pressures. Usually a urodynamic study will determine if you are a good candidate. If your present bladder system is working well there is no real reason to switch methods of bladder management.



The ideal candidate is an individual with a complete SCI who periodically has bladder incontinence and frequent bladder infections with the present bladder management method. You must be able to transfer to a toilet or wear a condom catheter to collect the urine when the system is used.

The system has yet to be fully implemented in Arkansas and just recently has become available at the Baptist Health Medical Center in Little Rock. If you, or someone you know, want to learn more about the system or to be assessed you can learn more at the following web site: **www.neurocontrol.com**, or call the company, NeuroControl at **1-888-333-4918**.

We're Updating Our Website

Due to personnel changes, the ASCC website, **www.state.ar.us/ascc**, has gotten behind the times and needs updating. So, we are now in the process of revising the website.

The site presently contains information about the agency and services we offer. Copies of the legislation that created the agency are available. Our fact sheets and past issues of *Spinal Courier* are on the website and ready to be downloaded. Also, information on the

ADA, statistics about spinal cord disability and long term care information are listed.

Our revised website will be including news of upcoming events that are of interest to our clients and spinal cord disability professionals. The updated site will also have links to other related websites.

We would like to know what **you** would like to see on our website. E-mail us at **arkscs@aol.com** with your ideas!

CAPPS Project

Continued from page 3

plan; the control group received no instructions.

The number of sores in the control group at clinic one was 15; at clinic three it remained 15. The number of sores at clinic one for the intervention group was 24; at clinic three, the number had decreased to 13.

The severity of sores was measured by the sum of all severity scores of all participants in each group. (Higher scores indicate sores of greater severity.) Severity scores for the control group a clinic one was 278 and by clinic three it had increased to 452. The clinic one sum for the intervention group was 546 and by clinic three it had decreased significantly to 350. The difference in severity scores between the control and intervention group was statistically significant ($p < .0001$).

The intervention group, who had worked through the prevention education material with their home health nurses, experienced a decrease in the number and severity of pressure sores. On the other hand, the control group who did not receive the home health nurse visits experienced no decrease in the number of sores and the severity of sores increased. Thus, it was concluded that a home education

prevention program can reduce and prevent pressure sores in persons with SCI.

So, how did the intervention group do it? What did they do that the control group did not? Turns out it wasn't one or two things but a combination of things. The intervention group made a difference by learning how to improve their lifestyle in a healthy manner. They learned to **exercise** more, **manage their stress** better, **improve their nutrition**, **receive more personal support**, and, most importantly, they learned to **take more responsibility for their own health**. In other words, they took a more active part in deciding their own health related activities.

So, what does this study have to do with you? I mean you're not like these study participants, are you? Maybe you've never had a pressure sore. What do you have to worry about?

Perhaps a lot. At the second clinic, all participants were asked to rate themselves for their risk of getting a pressure sore in 30 categories. At the same time the professional clinic staff rated each participant in the same categories. The results were very revealing. Participants tended to rate themselves as "low risk" in nearly every category. The



Physical Therapist Twala Maresh performs Xsensor Pressure Mapping to check for risk of pressure sores for CAPPS participant Lonnie Clark.

difference between the clinic staff and participant rating was significant ($p < .001$) and confirms that individuals with SCI tend to under-rate their pressure sore risk. In other words, **people with SCI tend to think that they are at low risk for developing a pressure sore, but their actual risk may be much higher.**

How about you? What's your risk of developing a pressure sore? Do you inspect your skin every day? Do you exercise/stretch enough? Are you eating healthy? Do you use a cushion on every seating surface? Is **today** the day **you** decide to take greater responsibility for your own health?

Next time in *What You Should Know about CAPPS, Part 2*, we'll look at some of the general characteristics of this study population.

Independence

Continued from page 6

process is very complex, so talk to a professional if you want to buy a home. To find a housing counselor in your area, contact Fannie Mae HomePath® Services at **1-800-732-6643** (www.homepath.com) or the National Home of Your Own Alliance at **1-800-220-8770**.

Conclusion

The overall goal for most individu-

als with SCI is to have all those things that most everyone wants in life: a job, family and a home of their own. There are many more programs available to help you reach your goal. Many of these programs are hard to understand. You may have to provide proof that you have a disability. You may be asked to provide personal financial information. Before you can qualify for a program, you must know the process and requirements of the organizations providing the

assistance. It is up to you to investigate all of the programs to find and use the ones that are right for you. When you reach a point when you are truly as independent as possible, you will see that it was all worth the effort.

This article was reprinted with permission from Pushin' On, 19(1), January 2001, page 5. Pushin' On is a publication of the University of Alabama at Birmingham (UAB) Medical Rehabilitation Research and Training Center on Secondary Conditions of SCI and UAB Model SCI Care System.

More Incentives on the Road to Independence

By Phil Klebine, Editor, *Pushin' On*

Many readers of *Incentives to Get You Working* were surprised by the work incentives offered by the Social Security Administration. [See the January 2001 issue of *Spinal Courier*.] However, most everyone wanted to know more, so this article briefly highlights other incentive programs that may help individuals with spinal cord injury (SCI) maximize their independence.

Buying a Car or Van



Lack of transportation is a major issue for many individuals with SCI. Public transportation does not exist in all areas and is often limited and unreliable where it does exist. There are some people who

could, and would, drive if they had the money for a car or van. The problem is many cannot afford the high monthly payment for a car or van. However, most large automakers such as Chevrolet, Ford and Chrysler offer extended financing for people with disabilities to help bring down the monthly payment. Those who qualify get extended financing from between 72 to 96 months. This means you can stretch payments for up to three years longer than most payment plans. Automakers may also provide a small rebate (usually up to \$1000) for selected adaptive equipment. Talk to your area dealership if you are interested because every program is different.

Home Financing



Owning a home is the American dream for most people. This is usually a dream never realized by many people with disabilities because they have low to moderate incomes and limited savings. Fannie Mae's HomeChoice program helps individuals with disabilities overcome these obstacles. The Fannie Mae Foundation works with lenders, mortgage insurers, state and federal government agencies and non-profit organizations across the country to help find various programs to assist with down payments, closing costs, cost for modifications and other costs necessary to buy a home. This

Continued on page 5 - see Independence

Wheelchair Parking

By Mark Hoyt, Clinton, AR



Recently I wrote a letter to the Commission about the wheelchair parking problem. In return, Cheryl Vines wrote back informing me of the act Representative Kim Hendren got passed for us. This was very good news indeed. But I would like to go a step further and address the disability problem from a different point of view.

At first there was a bill passed for people in wheelchairs allowing them to be able to park directly in front of a business. This was done for several reasons. One reason was that people in wheelchairs are low to the ground and someone might back into them as they travel from a distant parking space. Another reason is to allow an extra wide space to open the car door all the way to get in and out of the vehicle or to allow adequate space for vans equipped with chair lifts.

Soon, everyone with any kind of disability you could possibly think of joined in on the special parking spaces—and now the people in

wheelchairs can't find a place to park.

If we're going to let everyone with a disability park up front, then we need to design a system for everyone. This can be done very easily. All we need to do is create a new space for all the other people with disabilities that don't require a wheelchair.

I propose we have normal size spaces for these people, right next to the ones designated for wheelchairs. They don't require a wide space to park and three parking spaces can fit in the same space needed for two wheelchair spaces. We can save room and keep everyone happy at the same time.

There are signs now that say "handicapped" and would be perfect for these smaller areas. Their car tags could stay the same so there would not be any confusion. Everyone would be happy and people in wheelchairs could reclaim the parking spaces they

fought so hard to get.

I have been in a wheelchair for 23 years, and for 23 years I have had a problem finding a space to park. Why? Not because there are so many people in wheelchairs, but because there are so many people misusing the spaces made available. Every year I have witnessed more and more people obtaining handicap permits. Even if all the people who are misusing these spaces are made to stop, the problem of people in wheelchairs finding a place to park will remain. Although we have people like Cheryl Vines and Kim Hendren helping with this battle, I don't see people in wheelchairs regaining their spaces with the way things are now.

Cheryl informed me that this issue should be directed to our state representatives and senators. So, I am asking everyone who reads this and agrees with it to **write their legislators** so we can reclaim the space for wheelchair parking.

Jeremy's Wish Came True!

Eleven-year old Jeremy Wisham of Lake City, AR, born with spina bifida, is a true St. Louis baseball fan. He wished he could meet the Cardinals, especially his idol, Mark McGwire. His wish came true this past spring when he served as Honorary Bat Kid for the St. Louis Cardinals at their spring training camp in Florida.

On March 6 he left Memphis and flew to West Palm Beach, FL. Jeremy was accompanied on the trip by his parents, Randell and Carol Wisham, and his brother Jeffery, age 15. The next day he was the Honorary Bat Kid at the spring training game between the Cardinals and the Baltimore Orioles.

Cardinal Lou Brock escorted Jeremy to home plate as he presented

the Cardinals lineup cards. His name was displayed on the scoreboard and announced over the PA system. As he was leaving the field, Jeremy was presented a ball signed by some members of the Orioles team.

Jeremy met the members of the Cardinals team and got several autographs, including those of Hall of Famers Lou Brock and Red Schoendienst. Lou Brock told him he was a native Arkansan born in El Dorado. His favorite, though, was Mark McGwire. McGwire signed Jeremy's bat and told him to enjoy the game.

His father said, "I want to thank the Make-A-Wish Foundation and everybody in Paragould who contributed to make this possible." The Jonesboro chapter of the



Jeremy Wisham is very proud of the autographed bat he received while serving as Honorary Bat Kid for the St. Louis Cardinals at their spring training camp.

foundation had set a goal of \$5,000, but exceeded their target. The Jr. Food family of employees from the company's 17 Northeast Arkansas stores raised \$5,200 to fund Jeremy's trip. Jeremy is a very happy young man whose wish came true!

National Wheelchair Basketball Tournament Update

Arkansas was well represented in the National Wheelchair Basketball post-season tournaments this year! The Junior Rollin' Razorbacks were one of 16 teams that qualified for the National Junior Wheelchair Basketball Tournament (NJWBT) at Oklahoma State University in Stillwater, March 16 to 18. This was the Junior team's sixth appearance at the NJWBT.

Though the Junior Hawgs didn't fare well in the competition, their point guard Ryan Buchman won

the Sportsmanship award and was also selected to the NWBA Academic All American team. Buchman and teammates Tyler Garner and Kevin Hosea will represent the United States on the U.S. Junior National team competing in Sydney, Australia in October. Razorback Coach Doug Garner will serve as the U.S. Team Coach.

Not to be outdone by their Junior counterparts, the Rollin' Razorbacks upset the Music City Lightning in the South Division 1

regional tournament to qualify for their 13th consecutive trip to the National Wheelchair Basketball Tournament this year in Chicago on April 13 and 14. The Razorbacks lost in the semifinals to this year's national champions, the Golden State Road Warriors. It was still a good weekend for the Razorbacks, one of the winningest teams in NWBA history, as long-time Coach Harry Vines was elected to the National Wheelchair Basketball Hall of Fame, recognizing his role in the team's success.

SAILS Ninth DeGray Playday Coming Soon

SAILS (Spa Area Independent Living Services) in Hot Springs will hold its ninth DeGray Playday, Saturday, **August 25, 2001**, at the **Caddo Bend Swimming Area on DeGray Lake State Park**. This one-day, no cost event provides people with disabilities the opportunity to try recreational equipment usually taken for granted by the non-disabled world.

This year's activities include swimming, scuba diving, and riding jet skis, party barges and inner tubes. Land activities include volleyball, bingo and just plain old crowd watching.

As always, plenty of strong, young volunteers will be on hand to help participants on to and off of each activity. Picnic lunch will be served

at noon. Activities start at **10:00 a.m.** with Playday IX t-shirts given to the first 100 registrants.

Make your plans now to attend. For further information, call SAILS toll free at **1-800-255-7549v/tdd**, or in Hot Springs, **624-7710**.

Hope to see you there!

New Videos and Books in the Resource Center

The McCluer Education and Resource Center on Spinal Cord Injury has added a number of new items to its collection. If you are interested in checking out any of the resources, please call the Resource Center at **501-296-1792** or **1-800-459-1517**.

Dealing With Aging: Physical Function Presentation by Twala Maresh, P.T., (video) helps the aging person grow old gracefully and easily. With tips and advice from this skilled Physical Therapist, you can be sure to remain active long after you thought you might.

The Antibiotic Paradox – How Miracle Drugs Are Destroying the Miracle by Stewart B. Levy, M.D., (book) examines how the overuse of some antibiotics have caused problems in today's society.

Climbing Back by Mark Wellman and John Flinn, (book) encourages the disabled to accomplish great physical achievements and personal goals.

Disability in America by the Institute of Medicine, (book) details new groundbreaking approaches to the prevention

of disability. It also offers statistics on spinal cord injuries.

Sexual Rehabilitation of the Spinal Cord Injured Patient, edited by J.F.L. Leyson, M.D. While this book provides comprehensive coverage of sexuality in disabled persons, it has an additional focus on the psychosocial aspects of sexuality.

Quest For The Cure by the Paralyzed Veterans of America, (book) details new advancements in restoring function after spinal cord injuries.

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